

**Results of the Maine Experience Survey  
Adults with Physical Disabilities  
Consumer Directed Waiver**

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## Muskie School of Public Service

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## **Introduction from the Maine Department of Health and Human Services**

In 2001, the Maine Department of Health and Human Services received a three-year Real Choice Systems Change grant from the Centers for Medicare & Medicaid (CMS). One of the major goals of the grant was to ensure that the consumer voice and perspective was included in assessing and monitoring quality. Grant activities focused specifically on the Home and Community Based Waiver Programs administered by the Department. The Department contracted with the Muskie School of Public Service at the University of Southern Maine to conduct many of the activities identified in the grant under a Cooperative Agreement.

During the first year of the grant, an inventory was conducted to identify existing data sources and activities that were being used to evaluate the different waiver programs. As a part of grant activities, the need for a survey of consumers on the Consumer Directed Physically Disabled Waiver (also called the Consumer Directed or CD Waiver) was identified. This report provides the results of the in-home survey that was conducted by the Muskie School.

The CD Waiver serves people age eighteen and older with severe physical disabilities that meet nursing facility level of care, are their own guardian and have the ability and desire to self-direct the personal care services they receive in their home. The waiver is an alternative option to institutional care and consumers choosing community-based care are informed of the risks and limits to the care available in the community benefit. Unlike nursing facilities, twenty-four hour a day care is not available within the program limits.

The Department appreciates the time taken by the consumers who participated in this survey. This waiver benefit has experienced several administrative and program changes prior to and since the survey took place. The Department is interested in getting feedback from program participants following these changes. Their views can help identify areas of strength within the program as well as areas where improvement is needed.

The results of the survey identified some areas of focus and opportunities for increased training. The Department now requires the service provider to include as part of the skills training process with the consumer: (a) the need to formulate an emergency “back up” plan in case a care attendant is unable to care for the consumer, (b) training on the use of adaptive equipment, and (c) the necessity that all the CNA registry checks on attendants are completed as required by policy. Future surveys will be used to continue to monitor and address the quality and effectiveness of these services. The Department has contracted with the Muskie School of Public Service to conduct another consumer satisfaction survey in the next few months.

## Background and Methods

In August 2003, the Centers for Medicare & Medicaid released the Participant Experience Surveys (PES)<sup>1</sup> as a way to solicit feedback from HCBS waiver participants about the services and supports that receive. States can use the data from the surveys to calculate performance indicators, guide quality improvement projects and inform other parts of other quality management activities. The Participant Experience Surveys were developed by the Medstat Group in consultation with an expert panel of stakeholders, policy makers and researchers.

As indicated previously, one of the needs that had been identified as part of the Quality Choices I grant was the lack of a consumer survey for people on the Consumer Directed Waiver. In the fall of 2003, the Muskie School of Public Services contacted the Medstat Group to ask for assistance with the development of a version of the Participant Experience Survey (PES) for people on the consumer directed waiver. The purpose of this assistance was to modify, adapt and develop new questions that were relevant for people who hire and manage their own workers. An agreement was developed between the Medstat Group, the Muskie School of Public Service and Maine Department of Human Services to develop such a survey.<sup>2</sup>

At that time, the Consumer Directed Waiver was administered by the Department of Labor. Muskie staff worked with staff from the Department of Labor to identify the issues that were of particular concern and unique to the CD waiver. Staff from Medstat provided assistance and participated in meetings in Maine and via phone. Staff from the Bureau of Medical Services and the Bureau of Elder and Adult Services provided review and comments on the drafts as well.

Early versions of the PES-consumer directed survey were shared with the Consumer Advisory Group of the Department of Labor. Staff from the Medstat group and Muskie School staff participated in a meeting of that group.

As part of the grant, a Quality Technical Advisory Group (Quality TAG) was formed that included representatives of consumers, advocacy organizations, providers, other stakeholders and agency/department representatives. The Quality TAG provided review and comments on at least two versions of the survey. Staff from Alpha One, the agency responsible for training and payroll functions also provided ongoing review and comments.

The Muskie School's Survey Research Unit also participated in the design and testing of the instrument. The University of Southern Maine's Institutional Review Board reviewed and approved the protocols for the consent forms and conducting the interviews.

The instrument was field tested in three different and iterative cognitive tests with a combination of trained interviewers and project staff. Three or four people were interviewed as part of each

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<sup>1</sup> The PES versions include an elderly and non-elderly adults with physical disabilities version as well as individuals with mental retardation or developmental disabilities version. The PES provides indicators of the participants' experience in four areas: Access to Care; Choice and Control; Respect/Dignity; Community Integration/ Inclusion.

<sup>2</sup> This work was conducted under the National Quality contract with the Centers for Medicare and Medicaid.

cognitive test. A debriefing was held after each cognitive test and further revisions made to the instrument.

Training was held in late June 2004 for the interviewers in the Survey Research Unit on the instrument. In August of 2004, the administration of the consumer directed waiver program was transferred from the Department of Labor to the Bureau of Elder and Adult Services within the Department of Human Services. Staff from the Bureau of Elder and Adult Services and the Muskie School participated in the training. Final revisions to the instrument were made after the training. The interviewers started interviewing people in mid-July, 2004 and completed all interviews in October 2004.

## **Survey Results**

A total of 265 potential participants were identified. Criteria for being interviewed included being an active participant on the Consumer-Directed Waiver as of June 2004. Sixty-seven percent of the participants (177 people) completed the survey. Reasons for not participating in the survey included: person decline to participate; and/or phone number was no longer in service or incorrect. Over ninety-percent of the interviews were conducted in person; the remainder were conducted by phone. Interviews took, on average, thirty-minutes to conduct.

The following report presents the results of the survey including selected comments made as part of the open ended questions and other comments collected by the interviewers during the survey.

1. How did you first learn about the consumer-directed waiver services you receive through Alpha One?

|   |     |
|---|-----|
| <b>Alpha One Staff</b> .....  | 27% |
| <b>Friend/Family</b> .....  | 19% |
| <b>Medical Provider</b> .....   | 16% |
| <b>Home Health Provider</b> .....   | 6%  |
| <b>I Don't Remember</b> .....   | 6%  |
| <b>State Staff</b> .....  | 5%  |
| <b>Vocational Rehab</b> .....   | 3%  |
| <b>Program Literature</b> .....   | 2%  |
| <b>Goold</b> .....  | 2%  |
| <b>EIM</b> .....  | 1%  |
| <b>Disability Organization</b> .....  | 1%  |
| <b>Advocacy Group</b> .....   | 1%  |
| <b>Unsure</b> .....   | 4%  |
| <b>Other (included hospital, rehab center,<br/>other disabled person)</b> ..... | 25% |

2. Were you receiving other services at home prior to entering this consumer-directed program?

|                     |     |
|---------------------|-----|
| <b>Yes</b> .....    | 41% |
| <b>No</b> .....     | 59% |
| <b>Unsure</b> ..... | 1%  |

3. Where did you get these services?

- **Visiting Nurses**
- **Home Health Care Agency**
- **EIM**

4. What type of services did you receive?

- **nursing services**
- **personal care**
- **therapy**



5. What other services in Maine have you heard about that you could receive in your home?

|  |     |
|--|-----|
| <b>None</b> .....                                | 48% |
| <b>MaineCare Home Health Services</b>            |     |
| <b>(Nursing Services, Therapies)</b> .....       | 16% |
| <b>Other Home Care Services</b>                  |     |
| <b>(CD, Non-CD, Homemaker, Adult Day)</b> .....  | 11% |
| <b>Other Alpha One Programs</b> .....            | 9%  |
| <b>Medicare Home Health Services</b>             |     |
| <b>(Skilled Nursing, Aides, Therapies)</b> ..... | 5%  |
| <b>Other Waiver</b>                              |     |
| <b>(Adult w/Disabilities, Elderly, MR)</b> ..... | 4%  |
| <b>Private Pay Services</b> .....                | 3%  |
| <b>EIM</b> .....                                 | 3%  |
| <b>Private Duty Nursing (PDN)</b> .....          | 1%  |
| <b>Counseling</b> .....                          | 1%  |
| <b>Unsure</b> .....                              | 5%  |
| <b>Unclear</b> .....                             | 1%  |
| <b>No Response</b> .....                         | 1%  |
| <b>Other (included Meals on Wheels and</b>       |     |
| <b>Independent Living Services)</b> .....        | 18% |

6. How many P.A.s do you currently have, not including any back-up or standby P.A.s?

|                              |     |
|------------------------------|-----|
| <b>None</b> .....            | 11% |
| <b>1</b> .....               | 30% |
| <b>2</b> .....               | 34% |
| <b>3</b> .....               | 15% |
| <b>4</b> .....               | 3%  |
| <b>5</b> .....               | 6%  |
| <b>6</b> .....               | 1%  |
| <b>7</b> .....               | 0%  |
| <b>8</b> .....               | 1%  |
| <b>Not Ascertained</b> ..... | 1%  |

7. How many of these did you know before you hired them?

|                   |     |
|-------------------|-----|
| <b>None</b> ..... | 29% |
| <b>1</b> .....    | 33% |
| <b>2</b> .....    | 28% |
| <b>3</b> .....    | 8%  |
| <b>4</b> .....    | 1%  |
| <b>5</b> .....    | 1%  |
| <b>6</b> .....    | 1%  |

8. For those that currently have a P.A., how many of these P.A.s are family members or relatives? (n=156)

|                   |     |
|-------------------|-----|
| <b>None</b> ..... | 47% |
| <b>1</b> .....    | 30% |
| <b>2</b> .....    | 20% |
| <b>3</b> .....    | 3%  |

9. Now I want to ask you about your back-up or standby P.A.s. How many back-up or standby P.A.s do you have?

|                         |     |
|-------------------------|-----|
| <b>None</b> .....       | 45% |
| <b>1</b> .....          | 24% |
| <b>2</b> .....          | 21% |
| <b>3</b> .....          | 7%  |
| <b>4</b> .....          | 2%  |
| <b>5</b> .....          | 1%  |
| <b>Don't Know</b> ..... | 1%  |

10. For those that currently have backup or standby P.A.s, how many of these P.A.s are family members or relatives? (n=98)

|                              |     |
|------------------------------|-----|
| <b>None</b> .....            | 46% |
| <b>1</b> .....               | 34% |
| <b>2</b> .....               | 16% |
| <b>3</b> .....               | 1%  |
| <b>4</b> .....               | 1%  |
| <b>Don't Know</b> .....      | 1%  |
| <b>Not Ascertained</b> ..... | 1%  |

11. How have you located the P.A.s you did not already know? (n=51)

|   |     |
|---|-----|
| <b>Newspaper/Other Ad</b> .....   | 61% |
| <b>Through Personal Contacts/Friends</b> .....  | 25% |
| <b>NA - Knew All P.A.s Before Hiring</b> .....  | 18% |
| <b>Through Alpha One</b> .....  | 10% |
| <b>Other Alpha One Consumers</b> .....  | 4%  |
| <b>Church/Other Community Organization</b> .....  | 2%  |
| <b>Job Services/Career Center</b> .....   | 2%  |
| <b>Disability Group</b> .....   | 2%  |
| <b>Other (included bulletin board posting,<br/>through other PAs, local hospital)</b> ..... | 12% |

12. What is the longest time it has taken you to find and hire a P.A.?

|                                 |            |
|---------------------------------|------------|
| <b>One week or less.....</b>    | <b>45%</b> |
| <b>Two weeks or less.....</b>   | <b>19%</b> |
| <b>One month or less.....</b>   | <b>15%</b> |
| <b>More than one month.....</b> | <b>18%</b> |
| <b>Unsure.....</b>              | <b>2%</b>  |
| <b>No Response.....</b>         | <b>1%</b>  |

13. What caused the delay? Low pay and compatibility were mentioned most often. Other comments included:

- “There are no benefits”
- “They didn’t understand duties involved”
- “Lack of pay influenced the number of people who applied and the quality of the applicants.”

14. What did you do in the meantime?

Many said they relied on family members. One person’s husband took time off from work to help respondent while another went with husband to his office during the day. Two were in the hospital. Some had PAs who worked extra hours until new PA started. Six respondents said they were alone, went without help while waiting for PA to start.

15. The question “who do you consider to be your main P.A.?” was used to help focus the questions about their P.A.s.

16. Did you choose your main P.A. from among more than one applicant?

|  |            |
|--|------------|
| <b>Yes .....</b>                             | <b>39%</b> |
| <b>No .....</b>                              | <b>55%</b> |
| <b>Not applicable (only wanted one).....</b> | <b>5%</b>  |
| <b>Unsure.....</b>                           | <b>1%</b>  |

17. Would you recommend your main P.A. to a friend who needed the same kind of assistance?

|                    |            |
|--------------------|------------|
| <b>Yes .....</b>   | <b>94%</b> |
| <b>No .....</b>    | <b>4%</b>  |
| <b>Unsure.....</b> | <b>2%</b>  |

18. In the past year did you find it difficult to keep P.A.s?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>25%</b> |
| <b>No .....</b>         | <b>74%</b> |
| <b>No response.....</b> | <b>1%</b>  |

19. Why did you find it difficult to retain P.A.s? (n=44)

|   |            |
|---|------------|
| <b>Salary Too Low .....</b>   | <b>55%</b> |
| <b>No Benefits .....</b>  | <b>30%</b> |
| <b>Interpersonal Issues .....</b>   | <b>23%</b> |
| <b>Work too Difficult.....</b>  | <b>20%</b> |
| <b>Other (included unreliability, scheduling conflicts,<br/>not enough hours, personal issues).....</b> | <b>55%</b> |

20. Do you receive enough training from Alpha One on how to hire your P.A.s?

|                               |            |
|-------------------------------|------------|
| <b>Yes .....</b>              | <b>94%</b> |
| <b>No .....</b>               | <b>4%</b>  |
| <b>Unsure.....</b>            | <b>2%</b>  |
| <b>Unclear response .....</b> | <b>1%</b>  |

21. Do you receive enough training from Alpha One on how to train your P.A.s?

|                               |            |
|-------------------------------|------------|
| <b>Yes .....</b>              | <b>88%</b> |
| <b>No .....</b>               | <b>8%</b>  |
| <b>Unsure.....</b>            | <b>2%</b>  |
| <b>Unclear response .....</b> | <b>2%</b>  |
| <b>No response.....</b>       | <b>1%</b>  |

22. Do you receive enough training from Alpha One on how to manage your P.A.s?

|                               |            |
|-------------------------------|------------|
| <b>Yes .....</b>              | <b>94%</b> |
| <b>No .....</b>               | <b>2%</b>  |
| <b>Unsure.....</b>            | <b>3%</b>  |
| <b>Unclear response .....</b> | <b>1%</b>  |
| <b>No response.....</b>       | <b>1%</b>  |

23. Do you receive enough training from Alpha One on how to resolve problems with your P.A.s?

|                               |            |
|-------------------------------|------------|
| <b>Yes .....</b>              | <b>90%</b> |
| <b>No .....</b>               | <b>5%</b>  |
| <b>Unsure.....</b>            | <b>5%</b>  |
| <b>Unclear response .....</b> | <b>1%</b>  |

24. Do you receive enough training from Alpha One on how to develop a back-up plan?

|                               |            |
|-------------------------------|------------|
| <b>Yes .....</b>              | <b>82%</b> |
| <b>No .....</b>               | <b>11%</b> |
| <b>Unsure.....</b>            | <b>6%</b>  |
| <b>Unclear response .....</b> | <b>1%</b>  |
| <b>No response.....</b>       | <b>1%</b>  |

25. What additional training or assistance would you like?

- . Database of PAs who are aware of pay scale, hours and are willing to do this work, better list of PAs, help with finding PA, be able to find people, how to keep a PA as standby when they want to have a schedule, hiring pool for PAs, help with backups for PAs, help on weekends;
- . Driving program-help me get driver's license renewed;
- . 6 said more hours – survey was conducted prior to change back up to 86 hours;
- . Standardized training on back care and safety for PAs – we have had several PA back injuries, safety training for PAs, OT related things would be useful-body mechanics;
- . How to cope in emergency situations, what to do when no one else is around;
- . Filling out forms-it is on computer now but not developed enough;
- . Health insurance for PAs (mentioned by 2);
- . Help to go back to school;
- . Could use updates on new methods to make PA's job easier; new PAs need training for helping bed ridden clients; someone who does therapy to show me some exercises to help;
- . Tips on how to handle PAs-some people don't know how to ask for what they need in a tactful way so they don't ask, plain old 'manner' training;
- . Info re: how labor laws affect what you can and cannot say to PA-how far I can go without breaking employee rights;
- . If Alpha One could send someone over who's experienced for the first couple of days when a new PA comes on;
- . Help on screening people, background checks, interviewing, telephone responses;
- . Help in figuring out how to send my people to training, conflict resolution, when to let someone go, interviewing, backup plan;
- . Booklet is very helpful-she referred to it a lot, more detail on basic training than manuals provide;

26. Do you have any medical or other needs, such as catheter care, ventilator care, or use of a Hoyer lift, where your P.A. would need special training?

**Yes** ..... 46%  
**No** ..... 54%

27. What specific needs do you have that require special training? (n=81)

**Hoya Lift** ..... 57%  
**Catheter Care** ..... 44%  
**Bowel Regime**..... 23%  
**Ventilator Care**..... 9%  
**Wound Dressing**..... 9%  
**Supplemental Oxygen**..... 6%  
**Range of Motion** ..... 6%  
**Nebulizer**..... 5%  
**Tube Feeding**..... 4%  
**Other (included prosthesis care, positioning, transfer, urostomy, colostomy, gait belt, wheelchair use, medical equipment, oxygen, respiratory therapy, C-pap machine, injections, ceiling lift)** ..... 41%

28. Do you have enough support available for training your P.A. in these skills? (n=82)

|                               |     |
|-------------------------------|-----|
| <b>Yes</b> .....              | 85% |
| <b>No</b> .....               | 10% |
| <b>Unsure</b> .....           | 4%  |
| <b>Unclear response</b> ..... | 1%  |

29. In the past year, have you ever been unhappy with the way your P.A.s perform their work?

|                  |     |
|------------------|-----|
| <b>Yes</b> ..... | 28% |
| <b>No</b> .....  | 72% |

30. With which aspects of your P.A.s performance have you been unhappy? (n=50)

|  |     |
|--|-----|
| <b>How Work Gets Done</b> .....  | 58% |
| <b>P.A. Timeliness</b> .....   | 44% |
| <b>P.A. Reliability</b> .....  | 42% |
| <b>P.A. Attitude/Personality</b> .....   | 38% |
| <b>P.A. Ability to do Tasks</b> .....  | 16% |
| <b>Theft by P.A.</b> .....   | 8%  |
| <b>Unclear Response</b> .....  | 2%  |
| <b>No Response</b> .....   | 2%  |
| <b>Other (boundaries sometimes ignored, they bring their personal life to work, time management)</b> ..... | 22% |

31. What actions do you take if a P.A. repeatedly does not do what you ask him/her to do? (n=50)

|  |     |
|--|-----|
| <b>Verbal Warning</b> .....  | 52% |
| <b>Terminate P.A.</b> .....  | 46% |
| <b>Written Warning</b> .....   | 8%  |
| <b>Nothing</b> .....   | 6%  |
| <b>Involve Alpha One</b> .....   | 6%  |
| <b>Not Applicable – P.A. Generally Does What is Asked</b> .....  | 6%  |
| <b>Wage Sanction/Cut Back Hours</b> .....  | 4%  |
| <b>No Response</b> .....   | 2%  |
| <b>Other (talk with them, retrain them, have written contract, Probation – “give them another chance, or even 2-3 chances, Because it is so hard to find someone else”</b> ..... | 28% |

32. Comments from people who said they do nothing in response to Q31:

- “I shut my mouth and go to my room. If I say anything there will be an upset and I have to concentrate on managing my pain. I have to put my efforts into that.”
- “... because she is my mom”

33. Has a P.A. ever asked you to sign a timesheet that was not accurate?

**Yes** ..... 3%  
**No** ..... 97%  
**Unclear response** ..... 1%

34. & 35. What happened and what actions did you take? (For those who answered Yes to Q33):

- One was a duplicate that I took to Alpha One and I came back and told her I wouldn't sign it. She told lies to Alpha One. There was a hearing and she didn't show up. She quit.
- PA tried to make her sign a timesheet that was not legitimate. "I did not sign it."
- It was nothing of any consequence and then I watched it carefully and let them know. It was ok after that. Some people need closer supervision.
- Person took her vacation time but didn't work. She was put on medical (?) probation for a month.

36. Have you ever fired one of your P.A.s?

**Yes** ..... 49%  
**No** ..... 50%  
**Unsure** ..... 1%

37. Why did you fire this person? (For those who answered Yes to Q36):

- **29** mentioned PA unreliable-not showing up, showing up late, not calling consumer when can't come to work.
- **21** fired PA because of theft
- **21** mentioned PA's job performance as reason for firing them.
- **7** described PA's personal issues that affected their performance:
  - Brought children over when they were sick
  - Had a boyfriend coming and calling-it was interfering with job
  - She brought her kids to work, or when they were not here she was on the phone with them.
  - Fighting and arguing with boyfriend late, went out when was supposed to be here at night
  - One had personal problems that interfered with my care.
  - Always came too early and always talking on the phone to her boyfriend.
  - She was a personal friend with too many issues. She wanted to be taken care of!
- **6** indicated they fired PA because of substance abuse-"starting to come to work drunk", "occasionally intoxicated", "drinking problems", "one was smoking pot", "she smoked when told not to", "was mean, and had been drinking".
- Personality reasons:
  - Argued all the time, wanted to do things her way.
  - Had an attitude problem.
  - Verbally abusive and always arguing with me.
  - Profanity and aggressive behavior
- "Many reasons-one was stealing my pills, another one's car never worked-she was undependable."
- "Several: one was hostile and domineering to the point that I felt threatened. Another couldn't perform satisfactorily. Some have simply not been reliable."

- “He wanted me to lie about his work history with me.”
- “It was not because of a problem. I found someone whose schedule better matched my needs.”
- “PA overmedicated consumer to keep her from arguing with her.”
- “Left me stranded at a store.”

38. Can you talk to an Alpha One staff person when you need to?

**Yes** ..... 95%  
**No** ..... 1%  
**Sometimes**..... 2%  
**Unsure**..... 1%  
**Unclear response** ..... 1%

39. Do Alpha One staff respond to your call within 24 hours?

**Yes** ..... 94%  
**No** ..... 2%  
**Sometimes**..... 4%

40. Do Alpha One staff help you when you ask for something?

**Yes** ..... 94%  
**No** ..... 1%  
**Sometimes**..... 3%  
**Not applicable (have not called)** ..... 1%  
**Unclear response** ..... 1%

41. Do Alpha One staff treat you with respect?

**Yes** ..... 98%  
**No** ..... 1%  
**Sometimes**..... 1%

42. Do you know who to contact if you have a complaint about Alpha One?

**Yes** ..... 63%  
**No** ..... 28%  
**Unsure**..... 8%  
**No response**..... 1%

43. Have you ever received information on how to file an appeal?

**Yes** ..... 79%  
**No** ..... 12%  
**Unsure**..... 9%



44. How does your experience with directing your own P.A.s compare to what you expected?  
Would you say harder than you expected, the same, or easier than you expected?

**Harder than I expected**..... 15%  
**Same as I expected**..... 36%  
**Easier than I expected**..... 44%  
**I didn't know what to expect**..... 2%  
**Unsure**..... 1%  
**Unclear response** ..... 1%  
**No response**..... 1%

45. Please explain how your experience with directing your own P.A.s compares to what you expected:

- . Very hard to find anyone to do the work
- . Harder sometimes, easier for the most part
- . Coming into it, it seemed like a lot of paperwork-once you get the hang of it, it is quite easy.
- . Initially harder, but once adjusted to it, it is very easy.
- . Have good PAs so not many problems
- . Trying to find workers, low wages give low skills and experience. If they become a CNA they go to work at the hospital.
- . Having the job description helps-we all know what to expect.
- . I've been blessed. PCAs are more than willing to do what I ask. As long as you are considerate of them, they are considerate of you.
- . Finding people and getting people to be honest
- . Not hard to keep track of the hours they do and do the time sheet and mail it in.
- . A little leery about asking daughter (PA) to do things, but have had no problems.
- . Once I realized how everything was done and what I need to do, I found it easy to do. There is a fair amount of paperwork so it can't be put off.
- . It's gone much smoother than expected.
- . I try to have good PCAs that care about their jobs which makes it easier for me.
- . You get someone who doesn't know anything about assistance. You have to train them. Sometimes individuals get embarrassed by the duties they have to perform. Sometimes it's perfect. You can't just judge by one person.
- . It's gone well and Alpha One provides good support.
- . At first, it made me a little nervous with the paperwork but now it's fine.
- . It was harder than I thought. I need to be persistent and I can do it. I don't have a family for backup. It's worth the effort to be able to stay at home.
- . Somewhat difficult to direct others but consumer likes that she can choose compatible people.

46. Would you recommend the services and supports you get from the consumer-directed waiver to a friend who needed the same kind of assistance?

**Yes** ..... 98%  
**No** ..... 2%

47. Did you participate as much as you wanted to in developing your service plan?

**Yes** ..... 95%  
**No** ..... 3%  
**Unsure**..... 2%

48. In the last 60 days, have you ever been unable to complete a personal care task because you didn't have someone to assist you?

**Yes** ..... 16%  
**No** ..... 84%

49. What task(s) were you unable to do because no one was there to assist you? (n=29)

**Bathing**..... 34%  
**Using the Toilet**..... 28%  
**Personal Hygiene** ..... 24%  
**Dressing** ..... 24%  
**Transferring from a Bed or Chair to Wheelchair or Standing**.... 24%  
**Eating** ..... 17%  
**Bowel Program** ..... 10%  
**Taking Medicine** ..... 7%  
**Catheter Care** ..... 7%  
**Other (fell and couldn't get up until PA arrived, fell forward in chair, fell in bathtub, everything-I was in bed until 4pm when PA didn't show up, getting something to drink, fell out of bed, called EMT three times at night because no one stays at night, everything)** ..... 41%

50. Why was there no one to assist you? (n=29)

**Other** included "between shifts", "PA sick", "during hours no PA present"

**Not enough hours**..... 52%  
**PA didn't show up** ..... 20%  
**Other**..... 28%

51. In the last 60 days, have you ever been unable to complete a household task, such as laundry or preparing food, because you didn't have someone to assist you?

**Yes** ..... 14%  
**No** ..... 85%  
**Unsure**..... 1%  
**Unclear response** ..... 1%

52. What task(s) were you unable to do because there wasn't someone to assist you? (n=24)

|   |     |
|---|-----|
| <b>Housework</b> .....  | 50% |
| <b>Meal Preparation</b> .....   | 50% |
| <b>Laundry</b> .....  | 38% |
| <b>Groceries</b> .....  | 17% |
| <b>No Response</b> .....  | 4%  |
| <b>Other (unable to clean spill from floor; take out the garbage; picking up dog mess; messed in my bed and couldn't clean it; it tends to be when I'm between PAs and my other people are filling in; do dishes, make bed, vacuum; all of the above PA didn't show up)</b> ..... | 29% |

53. and 54. Why was there no one to assist you? (n=24). **Other** included "between shifts", "PA sick", "PA car problems", "during hours no PA present"

|                                |     |
|--------------------------------|-----|
| <b>Not enough hours</b> .....  | 50% |
| <b>PA didn't show up</b> ..... | 17% |
| <b>No response</b> .....       | 4%  |
| <b>Other</b> .....             | 29% |

55. Can you always get to the doctor's office or grocery store when you need to?

|                          |     |
|--------------------------|-----|
| <b>Yes</b> .....         | 89% |
| <b>No</b> .....          | 10% |
| <b>No response</b> ..... | 1%  |

56. Is there anything you want to do outside your home that you don't do now?

|                     |     |
|---------------------|-----|
| <b>Yes</b> .....    | 46% |
| <b>No</b> .....     | 54% |
| <b>Unsure</b> ..... | 1%  |

57. What would you like to do?

Many of the 81 who said Yes to Question 56 mentioned they would like to get out more. Other comments included wanting to work, shop, travel, go back to school, go to meetings, events, do yard work, and volunteer.

58. What do you need to make this happen?

Many mentioned transportation as a barrier to doing these activities. Others spoke of the need to have a PA or other person present to be able to do things outside the home.

59. When asked to describe their back-up system, most mentioned friends and family for assistance; some mentioned neighbors. A number of respondents have more than one P.A. and the P.A.s work together to make sure someone is available when one is sick or not available.

60. Have you ever had to use your back-up system?

|  |            |
|--|------------|
| <b>Yes .....</b>   | <b>65%</b> |
| <b>No .....</b>  | <b>25%</b> |
| <b>Not applicable (My backup system is not adequate) .....</b> | <b>8%</b>  |
| <b>Unsure.....</b>   | <b>8%</b>  |
| <b>No Response.....</b>  | <b>2%</b>  |

61. Why did you have to use it?

Most respondents had to use their backup system because the main PA was either sick or on vacation. Some used a backup system when they didn't have a main PA.

62. How did your backup system work?

113 answered. Some reported their backup worked "fine", "well", "great", and "good", while others reported it works "ok", "pretty well", "not bad", "it depends".

63. Have you ever felt unsafe because you did not have a P.A. present?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>31%</b> |
| <b>No .....</b>         | <b>68%</b> |
| <b>Unsure.....</b>      | <b>1%</b>  |
| <b>No response.....</b> | <b>1%</b>  |

64. Please tell more about feeling unsafe:

**15 respondents mentioned fear of falling or episode when they fell and no one was there to help them.**

- Had to call EMTs quite a few times because of falling half way out of wheelchair. Hurting myself, falling and no one here to help me.
- I'm afraid I might fall when I m alone and I would be stuck
- I have fallen from my chair and am unable to move myself from the chair at all. When my P.A. didn't show up I was in distress.

**14 respondents spoke of feeling unsafe when they are alone, with some specifying particularly at night, and 4 referred to hesitation in answering door when they are alone.**

- I get worried when I'm here alone...what if? I have a Life Line bracelet.
- Some time ago, I was alone on a very cold winter night and the phone wasn't working. I was stuck in bed and afraid
- One time, when I had my heart attack. At night it can be frightening especially since the heart attack
- Last night was the only time in several years I could not get someone here at night.....10 to 6 spot. It's an important slot.
- At night time if no one is here I feel vulnerable
- I don't feel comfortable answering the door when there is no one with me

**6 comments related to not being able to get from one place to another or feeling nervous when attempting that on their own, with no one present.**

- Sometimes feels unsafe, getting in and out of wheelchair to go to bathroom, slides up and down stairs, has distonia and feels vulnerable when left alone.
- I was in bed and had to find a backup that could come get me out of bed
- getting stuck in backyard or on ramp
- If I don't have anyone to put me to bed, I have to stay in the chair all night. I can have a diabetic reaction and there is not always someone here.

**Additional comments included:**

- when my PA is not home my husband barely leaves the house. I've passed out without warning
- the battery broke down on his wheelchair and he had to wait until someone came to move him and restart it
- PA put her in wheelchair and didn't have oxygen on and felt short of breath...called lifeline to send rescue...PA had gone out and was supposed to come back and didn't
- I was sick .....I used Life Alert to get an ambulance

65. Since you've been on the Consumer Directed waiver program, have you ever talked with anyone at Alpha One about any special equipment or changes to your home that might make your life easier?

**Yes** ..... 68%  
**No** ..... 31%  
**Unsure**..... 2%

66. What equipment or changes did you talk about?  
Equipment mentioned: Ramp, scooter, Hoyer lift, walk/roll in shower, wheelchair, bathroom modification, widen doorways

67. Did you get the equipment or make the changes you needed? (n=120)

**Yes** ..... 67%  
**No** ..... 23%  
**In process** ..... 8%  
**Unsure**..... 2%  
**No response**..... 1%

68. Reasons for not getting equipment or making changes included: cost (mentioned most often), Housing Authority does not allow it (mentioned twice related to walk in showers), waiting list

69. Would additional adaptive equipment allow you to be more independent?

**Yes** ..... 44%  
**No** ..... 47%  
**Unsure**..... 10%

70. What kinds of equipment? (n=77)

|   |            |
|---|------------|
| <b>Modified Van .....</b>   | <b>23%</b> |
| <b>Ramp .....</b>   | <b>14%</b> |
| <b>Hoyer Lift .....</b>   | <b>12%</b> |
| <b>Motorized Wheelchair.....</b>  | <b>6%</b>  |
| <b>Grab Bars.....</b>   | <b>5%</b>  |
| <b>Other (environmental control unit, automatic door opener,<br/>slide boards, track system-items that help with transferring).....</b> | <b>75%</b> |

71. Do your P.A.s treat you respectfully in your home?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>95%</b> |
| <b>No .....</b>         | <b>2%</b>  |
| <b>Sometimes.....</b>   | <b>2%</b>  |
| <b>No response.....</b> | <b>1%</b>  |

72. Do your P.A.s respect your privacy in your home?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>97%</b> |
| <b>No .....</b>         | <b>2%</b>  |
| <b>No response.....</b> | <b>1%</b>  |

73. Do your P.A.s respect confidentiality about your personal information?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>91%</b> |
| <b>No .....</b>         | <b>2%</b>  |
| <b>Unsure.....</b>      | <b>6%</b>  |
| <b>No response.....</b> | <b>1%</b>  |

74. Do your P.A.s listen carefully to what you ask them to do in your house?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>90%</b> |
| <b>No .....</b>         | <b>2%</b>  |
| <b>Sometimes.....</b>   | <b>6%</b>  |
| <b>No response.....</b> | <b>2%</b>  |

75. Have you ever been injured by any of your P.A.s?

|                         |            |
|-------------------------|------------|
| <b>Yes .....</b>        | <b>11%</b> |
| <b>No .....</b>         | <b>89%</b> |
| <b>No response.....</b> | <b>1%</b>  |

76. Most common incidents reported were burns, falls, or being dropped. Respondents also added that these were usually accidental. There were two comments related to being shoved or using excess force.

77. The timeframe for these incidents happening ranged from “4 months ago” to “several years ago”.

78. Would you like any help with this problem? (n=19)

|  |     |
|--|-----|
| <b>No</b> .....  | 21% |
| <b>Happened with a former PA/<br/>situation was resolved</b> ..... | 74% |
| <b>No response</b> .....   | 5%  |

79. Are any of your P.A.s mean to you, or do they yell at you?

|                          |     |
|--------------------------|-----|
| <b>Yes</b> .....         | 3%  |
| <b>No</b> .....          | 93% |
| <b>Sometimes</b> .....   | 2%  |
| <b>No response</b> ..... | 1%  |

80. When asked “what happened?” responses included:

“In the past I have had people that got too rough and we had words...”

“They think this way is best, I wanted it another way, sometimes [they] get angry...”

Some reported they fired the person; others “told her to stop”.

81. Would you like any help with this problem? (n=10)

|  |     |
|--|-----|
| <b>No</b> .....  | 40% |
| <b>Happened with a former PA/<br/>situation was resolved</b> ..... | 40% |
| <b>Unclear response</b> .....                                      | 10% |
| <b>No response</b> .....   | 10% |

82. Have any of your P.A.s ever taken your things without asking?

|                     |     |
|---------------------|-----|
| <b>Yes</b> .....    | 23% |
| <b>No</b> .....     | 75% |
| <b>Unsure</b> ..... | 1%  |

83. Thirteen people reported money being stolen; six people reported medicine stolen. Others reported “making long distance calls from my phone” and “sometimes he used computer wrong way”. The P.A. being fired was often the end result.

84. When asked when this happened, time span was from “this year” up to “years ago”.

85. Would you like any help with this problem? (n=41)

**No** ..... 22%  
**Happened with a former PA/  
situation was resolved** ..... 76%  
**Unclear response** ..... 2%

86. Is there a computer you use in your home?

**Yes** ..... 72%  
**No** ..... 28%

87. Is there a computer you use somewhere else? (n=51)

**Yes** ..... 16%  
**No** ..... 82%  
**No response** ..... 2%

88. Does that computer have Internet access? (n=134)

**Yes** ..... 93%  
**No** ..... 7%

89. How would you rate your current health overall? Would you say excellent, very good, good, fair or poor?

**Excellent** ..... 12%  
**Very good** ..... 23%  
**Good** ..... 24%  
**Fair** ..... 27%  
**Poor** ..... 14%  
**No response** ..... 1%

90. Additional comments at the end of the survey included a wide spectrum of responses.

**Many related to cutbacks being considered at time survey was being conducted.**

“Excellent program and I would be devastated if it was eliminated or cut back sharply. I would be in a nursing home and it has made an enormous difference in my quality of life.”

**A number of respondents mentioned the need for increased wage and benefits for P.A.s.**

Not an “adequate pool of qualified people to be P.A.s; doesn’t pay enough...isn’t competitive...needs to be increased”



**Many expressed appreciation and satisfaction with the support they receive from Alpha One.**

“Alpha One has always helped me...just call anytime need help”

91. Interviewer comments and observations:

- Many respondents were very cooperative, thoughtful with responses and happy to participate.
- Due to timing of the survey, many mentioned concern about state possibly making cuts in the program. Many of these proposed cuts did not occur.
- Respondents remarked on the positive relationship they have with Alpha One, the administrator of the Physically Disabled HCBS waiver.

92. Were there other people present during the interview?

**Yes** ..... 43%  
**No** ..... 57%

93. Who was present? (n=76)

**Spouse**..... 10%  
**Parent**..... 5%  
**Family**..... 9%  
**P.A.** ..... 26%  
**Other**..... 5%

94. Did the respondent want (this person/these people) present? (n=76)

**Yes** ..... 93%  
**Unsure**..... 7%

95. Were there any other factors affecting the interview (e.g., outside noise, respondent hearing loss, disruption by staff or others, etc.)?

**Yes** ..... 20%  
**Unsure**..... 80%

96. Interviewers were asked to “please describe.” Factors included noise at some of the interviews. Though noise, children and animals were factors mentioned by interviewers, these factors did not have a negative impact on the completion of interviews.

97. Interviewers were asked to “please describe the respondent’s overall state during the interview process.” Some respondents struggled, or had difficulty, communicating, but wanted to participate in the interview.

98. Did someone other than the consumer answer the survey questions?

|   |            |
|---|------------|
| <b>Yes .....</b>                            | <b>7%</b>  |
| <b>No .....</b>                             | <b>81%</b> |
| <b>Some questions/shared responses.....</b> | <b>11%</b> |
| <b>No response.....</b>                     | <b>1%</b>  |

99. Who answered for the consumer? (n=31)

|                          |            |
|--------------------------|------------|
| <b>Staff.....</b>        | <b>29%</b> |
| <b>Other Family.....</b> | <b>19%</b> |
| <b>Spouse.....</b>       | <b>16%</b> |
| <b>Parent.....</b>       | <b>16%</b> |
| <b>Other.....</b>        | <b>32%</b> |
| <b>NA.....</b>           | <b>3%</b>  |